

Research Highlights

Topic: Positive Behavior Support

Turnbull, A.P., & Ruef, M. (1996). Family perspectives on problem behavior. *Mental Retardation*, 34(5), 280-293.

BOTTOM LINE

Telephone interviews were conducted with 17 families who had a family member with mental retardation and/or problem behavior. Recommendations for future research and training emerged from the interviews that focused on family perceptions of problem behavior. Families defined problem behavior as either difficult or dangerous. They also shared details about the challenges they currently face, and made suggestions about the kinds of information and other assistance might help them and their family member with problem behavior.

TIPS

- Look for the reason or environmental factors behind a particular behavior, and seek to modify the behavior based on this knowledge instead of placing blame on the family.
- Devise a structured, predictable daily routine for the person with the dangerous or difficult behavior.
- Create opportunities for people with problem behavior to
 - communicate verbally or non-verbally with others.
 - establish friendships with people outside of the family circle.
 - make choices and experience the consequences of those choices.
- Create opportunities for families, including parents and siblings, to
 - have access to support in managing daily routines, including weekends, meals, and sleep-time.
 - expand relationships within the community.
 - make use of stress-management tools and techniques.

TIPS
cont.

- draw on the helpfulness of professionals and others with positive views, who share the family's experiences and vision for their family member with problem behavior.
- Consistent with state-of-the-art positive behavior support (PBS), teach the person with the problem behavior new skills, make changes in his or her environment, and modify the consequences of both positive and negative behaviors.

KEY FINDINGS

- Families shared challenges and successful approaches to dealing with their family member with problem behavior, its impact on the family, and family needs for resources and information about it.
- Families perceived problem behavior as being either difficult or dangerous. Contrary to research expectations, families discussed difficult behaviors more often than dangerous behaviors.
- Problem behavior was defined as aggression towards others, property destruction, self-injurious behavior, or pica. (Pica is an at least one-month-long pattern of eating non-nutritive substances (such as dirt, paper, or chalk.)
- Parents described dangerous behavior matter-of-factly, saying that it was a source of constant worry and fear, even when the behavior was uncommon. Non-family members shared this perception.
- Families saw difficult behavior as a non-stop, successful demand for attention.
- Problem behavior brought out fear and worry among people who were or were not family members. Difficult behavior also prompted concerns, embarrassment, and/or annoyance in both of these groups.
- Families want to learn more about why problem behavior occurs, how to reduce or eliminate it, how to remain energetic in spite of day-to-day demands, and how to be active advocates for family members with problem behavior.
- Parents feel both empowered and drained by their own advocacy efforts, but at least half invested considerable time and energy into advocacy.
- Families recognized a need for comprehensive support including
 - access to dependable, trusted, nonjudgmental reliable allies
 - structured routines in the home for the benefit of their family member with problem behavior
 - enhanced verbal as well as non-verbal communication

KEY FINDINGS

cont.

- enhanced verbal as well as non-verbal communication
- an expanded circle of relationships for all family members
- increased self-determination and possibilities for making choices for the person with the problem behavior
- stress management for parents and siblings
- better information about problem behavior, positive behavior support, and other relevant resources.

METHOD

- Telephone interviews of 30-120 minute duration were conducted by 3 interviewers over 5 months with 17 families with a family member who had a disability and/or had displayed challenging behavior.
- The purposive, non-random sample of the participants in this study, which was part of a larger study, was chosen from among people who lived in different geographical locations. 15 mothers, 3 fathers, 1 sibling, and 1 friend/roommate participated in the study.
- Participants identified and described issues that were of importance to them, thereby helping to develop new hypotheses for future studies.

RELATED PUBLICATIONS

- Carr, E.G., Horner, R.H., Turnbull, A.P., Marquis, J.G., Magito-McLaughlin, D., McAtee, M.L., Smith, C.E., Ryan, K.A., Ruef, M.B., & Doolabh, A. (1999). *Positive behavior support as an approach for dealing with problem behavior in people with developmental disabilities: A research synthesis*. Washington, DC: American Association on Mental Retardation.
- Ruef, M.B., & Turnbull, A.P. (2002). The perspectives of individuals with cognitive disabilities and/or autism on their lives and their problem behavior. *Research and Practice for Persons with Severe Disabilities*, 27(2), 125-140.
- Ruef, M., & Turnbull, A.P. (2001). Stakeholder opinions on accessible informational products helpful in building positive practical solutions to behavioral challenges of people with mental retardation and/or autism. *Education and Training in Mental Retardation and Developmental Disabilities*, 36(4), 441-456.
- Turnbull, A.P., & Ruef, M. (1997). Family perspectives on inclusive lifestyle issues for individuals with problem behavior. *Exceptional Children*, 63(2), 211-227.
- Turnbull, A.P., & Turnbull, H.R. (2002). Comprehensive lifestyle support for adults with challenging behavior: From rhetoric to reality. In J. Lucyshyn, G., Dunlap, & R. Albin (Eds.), *Families and positive behavior support: Addressing problem behavior in family contexts* (pp. 57-72). Baltimore: Paul H. Brookes.

RELATED
PUBLICATIONS
cont.

Turnbull, H. R., Turnbull, A.P., & Wilcox, B. L. (2002). Family interests and positive behavior support: Opportunities under Individuals with Disabilities Education Act. In J. Lucyshyn, G. Dunlap, & R. Albin, (Eds.), *Families and positive behavior support: Addressing problem behavior in family contexts* (pp. 349-370). Baltimore, MD: Paul H. Brookes.

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